Information on the Internet for asplenic patients: a systematic review

Mark A. Downing, MD*
Ahmed H. Omar, MD†
Elham Sabri, MSc‡
Anne E. McCarthy, MD§

From the *Division of Infectious Diseases, University of Toronto, the †Department of Infectious Diseases, The Ottawa Hospital—General Campus, the ‡Ottawa Health Research Institute and the §Division of Infectious Diseases, Department of Internal Medicine, The Ottawa Hospital, Ottawa, Ont.

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Correspondence to:
Dr. M.A. Downing
Division of Infectious Diseases
University of Toronto
200 Elizabeth St.
Toronto ON M5G 2C4
mdowning@dal.ca

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Background: Asplenic patients in general have poor knowledge about their condition. Patients are increasingly turning to the Internet for their health care information, therefore this is a resource that many asplenic patients will use. The aim of our study was to determine the quality of information on the Internet for asplenic patients.

Methods: We identified websites by entering "splenectomy OR spleen removal" into 3 Internet search engines on July 28, 2008. The top 50 English-language websites from each search engine were included in our analysis. We evaluated the websites with our own 21-point content scale as well as 4 commonly used quality-assessment tools. All websites were analyzed independently by 2 reviewers. Correlations were made between the quality assessment instruments, content, readability and target audience.

Results: We included 89 websites in the study. The mean content score percentage for all websites was 49% (95% confidence interval 44%–54%). The long-term risk of infection was mentioned in 84% of websites, and the need for vaccination was mentioned in 79%. The mean quality assessment tool score was 61%, and the mean reading grade level was 11.

Conclusion: Whereas websites on average did not cover most of the information that asplenic patients should receive, the long-term risk of serious infection and the need for vaccination was consistently mentioned. Websites were inconsistent with respect to adhering to standards advocated by the quality assessment instruments we used, and the mean reading grade level was far above what is recommended for patient literature.

Contexte : Les patients aspléniques connaissent en général mal leur état. Les patients se tournent de plus en plus vers Internet pour trouver de l'information sur les soins de santé et il s'agit donc d'une ressource que beaucoup de patients aspléniques utiliseront. Notre étude visait à déterminer la qualité de l'information qu'offre Internet aux patients aspléniques.

Méthodes : Nous avons trouvé des sites web en entrant les expressions « splénectomie OU ablation de la rate » dans 3 moteurs de recherche sur Internet le 28 juillet 2008. Cette analyse a porté sur les 50 principaux sites web de langue anglaise trouvés par chaque moteur de recherche. Nous avons évalué les sites web au moyen de notre propre échelle comportant 21 points, ainsi que de 4 outils d'évaluation de la qualité d'usage courant. Deux examinateurs ont analysé indépendamment tous les sites web. On a établi des liens entre l'instrument d'évaluation de la qualité, le contenu, le niveau de lecture et le public cible.

Résultats : L'étude a porté sur 89 sites web. Le pourcentage du score moyen obtenu pour le contenu de tous les sites web s'est établi à 49 % (intervalle de confiance à 95 %, 44 % à 54 %). Le risque à long terme d'infection a été mentionné par 84 % des sites web et le besoin de vaccination a été mentionné par 79 % des sites. Le score moyen produit par l'outil d'évaluation de la qualité s'est établi à 61 % et le niveau moyen de lecture, à secondaire 5.

Conclusion : En moyenne, les sites web ne couvraient pas la majeure partie de l'information que les patients aspléniques devraient recevoir, même si l'on mentionnait fréquemment le risque à long terme d'infection grave et le besoin de vaccination. Les sites web manquaient d'uniformité en ce qui a trait à l'observation des normes préconisées par les instruments d'évaluation de la qualité que nous avons utilisés et le niveau moyen de lecture dépassait de loin celui que l'on recommande dans les publications destinées aux patients.

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Asplenic patients are an often overlooked group of immunocompromised patients who are at risk for serious infections. Overwhelming postsplenectomy sepsis (OPSI) is a well-characterized phenomenon that is typically caused by encapsulated bacteria such as *Streptococcus pneumoniae*, *Neisseria meningitidis* and *Hemophilus influenzae* type B. There are a number of important precautions that patients who have had splenectomies should undertake, including the receipt of vaccinations against these 3 bacteria. Compliance with these recommendations is poor worldwide, with recent pneumococcal vaccination rates ranging from 60% to 75%.[1–4] Therefore, many asplenic patients unnecessarily remain at high risk for OPSI following their splenectomies.

An important component of care pre- and postsplenectomy is patient education. Unfortunately, asplenic patients on average have very little knowledge about the implications of not having a spleen. Particularly in the case of trauma, the acuity of hospital admission makes it challenging to properly educate patients. Multiple studies have demonstrated that fewer than 50% of asplenic patients have adequate knowledge about the splenectomy state.[5,6] Furthermore, it has been shown that patients with the greatest knowledge about splenectomy have a far lower risk of OPSI compared with those with the least knowledge.[6] Patient education therefore plays an important role in postsplenectomy management.

The Internet is rapidly becoming the primary source of health care information for patients and their families. Recent studies have shown that 27%–60% of patients and their family members access the Internet for health care information.[7–10] There are no universal regulations to ensure that websites provide readable, accurate, up-to-date and unbiased information. Most patients are not trained in medical literature appraisal, and therefore the quality of information on the Internet has become a major concern. It has been shown that search ranks from search engines do not correlate with the quality of health care information on the websites.[11,12] Several guidelines have been published in an attempt to help with critical appraisal of websites by patients;[13–17] however, it is unclear how these are being used. As Internet use continues to grow, this will become an increasingly larger area of concern for patients and their health care providers.

Given that asplenic patients generally have inadequate knowledge about precautions that they should be taking and that the Internet is becoming an increasingly important source of health care information, we sought to assess the quality of splenectomy information for patients on the Internet.

Box 1. Components of the content score

1. Diagram indicating location of spleen
2. Immunologic role of spleen mentioned
3. Trauma as indication for splenectomy
4. Any nononcologic hematologic indication for splenectomy
5. Any oncologic indication for splenectomy
6. Description of both laparoscopic and open splenectomy
8. General perioperative surgical complications
9. Long-term risk of infection
10. Need for vaccination mentioned
11. Pneumococcal vaccine around the time of surgery
12. Hemophilus vaccine around the time of surgery
13. Menningococcus vaccine around the time of surgery
14. Vaccinations ideally more than 2 weeks before surgery
15. Pneumococcal vaccine repeated every 5–10 years
16. Annual influenza vaccine
17. Seeking medical advice for minor illness
18. Seeking medical advice before travel
19. Wearing a medical alert bracelet or carrying a splenectomy card
20. Antibiotic prophylaxis in children
21. Glossary of medical terms

Methods

Internet search strategy

We searched on Google, Yahoo and MSN because they were the 3 most popular search engines worldwide at the time of the study.[18] Websites were identified by entering "splenectomy OR spleen removal" into the 3 search engines on July 28, 2008. We evaluated the top 50 English-language websites listed on each search engine. We excluded websites from our final analysis if the information did not pertain to human splenectomy, if the website was a discussion forum, if membership was required for access, if the website contained a video rather than text and if the website was a portal.

Website review

All sites that we included in the study were analyzed independently by 2 of us (M.D. and A.O.). Webites were assessed using our own 21-point content score as well as 4 separate quality-assessment instruments that have been used in the literature. The content score (Box 1) was based on common information that should be given to asplenic patients and on the Advisory Committee on Immunization Practices for the Centres for Disease Control and Prevention,[19] the Canadian Immunization Guide[20] and the British Committee of Hematology Standards.[21] The 4 quality-assessment instruments used were the *Journal of the American Medical Association* (*JAMA*) benchmarks,[13] Health On the Net Code of Conduct (HON),[16] DISCERN[17] and Minervation.[22] Their characteristics are listed in Box 2. All scores were expressed as a fraction of the total score for each instrument.

We generated readability scores using the Flesch Reading Ease Scale and Flesh–Kincaid Reading Level, which have been described previously in systematic reviews.[23,24] The Flesch Reading Ease Scale scores text based on the number of words per sentence and the number of syllables per word, with a higher score indicating easier text. The

Flesh–Kincaid Reading Level uses a similar formula to generate a school grade level for which the text is appropriate (up to grade 12). To calculate these scores, we copied a representative 100- to 200-word excerpt from each website into Microsoft Word.

Statistical analysis

Interrater reliability was assessed for all scoring scales using intraclass correlation coefficients. If scores differed by more than 20% between the 2 reviewers for the quality assessment instruments or the content score, the website was reassessed by both reviewers, and a common score was agreed on. For differences less than 20%, a mean of the 2 scores was used. We calculated the mean content, quality-assessment instrument and readability scores for all websites. We also looked at mean percentage scores for the individual components of the content score.

RESULTS

The Internet search yielded a list of 103 websites. We excluded 14 websites from the analysis for the following reasons: 7 required membership, 1 was a portal, 1 was a forum, 2 were video-only and 3 were not related to human splenectomy. The remaining 89 websites were included in the analysis.

Interrater variability, expressed as intraclass correlation (and 95% confidence intervals [CIs]), was low for all quality-assessment instruments: *JAMA* 0.85 (0.78–0.90), HON 0.73 (0.62–0.81), DISCERN 0.82 (0.78–0.88) and Minervation 0.86 (0.79–0.91). The content score also showed very little variability with an intraclass correlation coefficient of 0.88 (95% CI 0.82–0.92). The Flesh–Kincaid formula and Reading Ease Scale showed intraclass correlations (and 95% CIs) of 0.66 (0.53–0.76) and 0.73 (0.62–0.81), respectively.

The mean content score percentage for all websites was 49% (95% CI 44%–54%). Table 1 indicates the percentage of websites that addressed each component of the content score. About 50%–72% of the content of each website focused on the surgery itself compared with 14%–79% content on vaccinations and 17%–67% content on precautions. The long-term risk of infection was mentioned in 84% of websites. Whereas vaccination in general (79%) and pneumoccal vaccination in particular (62%) were consistently recommended, hemophilus (27%) and meningococcal (35%) vaccinations were less often mentioned. Results were similar for all websites, regardless of whether they were designed to be patient-oriented.

Websites showed little variability in terms of performance based on the quality-assessment instruments. Mean percentage scores (and 95% CIs) for all websites were as follows: *JAMA* 57% (51%–63%), HON 61% (57%–65%), DISCERN 60% (57%–63%) and Minervation 64% (62%–67%). The mean Flesh Reading Ease Scale score was 32.26 (95% CI 28.99–35.51), and the mean Flesh–Kincaid reading grade level was 11.

DISCUSSION

To our knowledge, this is the first review of information

Box 2. Summary of the criteria used by quality-assessment instruments

***JAMA* principles[13]**

1. Authorship: authors and contributors, their affiliations and relevant credentials
2. Attribution: references and sources for all content and relevant copyright information
3. Disclosure: website ownership, sources of sponsorship, advertising and conflicts of interest
4. Currency: dates that content was posted and updated

HON Code of Conduct[16]

1. Indicate the qualifications of the authors
2. Support, don't replace, the doctor–patient relationship
3. Respect the privacy and confidentiality of personal data submitted to the site by the visitor
4. Cite the sources of published information, date and medical and health pages
5. Back up claims relating to benefits and performance
6. Ensure accessible presentation, accurate email contact
7. Identify funding sources
8. Clearly distinguish advertising from editorial content

DISCERN[17]

1. Are the aims clear?
2. Does it achieve its aims?
3. Is it relevant?
4. Is it clear what sources of information were used to compile the publication?
5. Is it clear when the information used or reported in the publication was produced?
6. Is it balanced and unbiased?
7. Does it provide details of additional sources of support and information?
8. Does it refer to areas of uncertainty?
9. Does it describe how each treatment works?
10. Does it describe the benefits of each treatment?
11. Does it describe the risks of each treatment?
12. Does it describe what would happen if no treatment is used?
13. Does it describe how the treatment choices affect overall quality of life?
14. Is it clear that there may be more than 1 possible treatment choice?
15. Does it provide support for shared decision-making?

Minervation validation instrument[22]

1. Is the site accessible?
2. Is the site design clear and transparent?
3. Is the site design consistent from one page to another?
4. Can users find what they need on the site?
5. Is the format of information clear and appropriate for the audience?
6. Is it clear who has developed the website and what their objectives are?
7. Does the site report a robust quality-control procedure?
8. Is the page content checked by an expert?
9. Is the page updated regularly?
10. Does the page cite relevant sources where appropriate?

DISCERN = Drosoph Inf ServCERN; HON = Health on the Net; *JAMA* = *Journal of the American Medical Association.*

for asplenic patients on the Internet. Websites in general contained less then 50% of the information that should be given to patients undergoing splenectomy. However, the 2 most important topics were covered consistently throughout most websites: the long-term risk of infection was mentioned in 84% of websites and the need for vaccination mentioned in 79% of websites. Pneumococcal vaccination was also consistently covered, with fewer websites mentioning Hemophilus and meningococcal vaccination. Whereas *Streptococcus pneumonaie* is the most established cause of overwhelming postsplenectomy sepsis, *Neisseria meningitis* and *Hemophilus influenzae* type B are other vaccine-preventable pathogens, and information should emphasize coverage for all 3 bacteria. Other important deficits in the online literature are the importance of annual influenza vaccination (to prevent secondary pneumococcal pneumonia) and travel advice (primarily to prevent severe malaria infection).

Quality-assessment instruments have been advocated as a means to help determine the credibility of a website. For example, the *JAMA* benchmarks rely on the inclusion of 4 basic elements: authorship, references, date of publication and disclosure of sponsorship. The websites in our analysis performed modestly based on these instruments, with a mean score of 61%. There continue to be large deficits in how websites report information to demonstrate that they are unbiased, transparent and reliable. Unfortunately, there is no way to regulate health information on the Internet and, therefore, these deficits will probably persist.

Perhaps what is most surprising is that the mean reading grade level for all websites was grade 11, which is far above the generally recommended reading level of grade 6 for patient information. We intentionally included websites oriented to patients and professionals since patients have access to both. Making patient information readable is certainly a challenge to authors, as the more detailed the content, the harder it is to read. This study demonstrates that high reading levels probably represent a large barrier for patients who wish to access information on the Internet. The quality of a website's information is irrevelant if the reader cannot understand the information in the first place.

There are several potential limitations to our study. The website review was performed by 2 physicians, which may not accurately reflect how a patient might interpret a website. For instance, in terms of the DISCERN criteria, physicians and patients may disagree on which websites are relevant. Furthermore, patients may not be able to understand important parts of the text, which is why we chose to emphasize readability scores.

We did not assess websites for false information, therefore the content score might not completely represent the

Table 1. Percentage of websites that addressed each component of the content score, with comparisons among all, patient-oriented and other websites

	Type of website; no. (%)		
Topic	All *n* = 89	Patient-oriented *n* = 62	Other *n* = 27
Any diagram indicating the location of the spleen	43 (48)	38 (61)	5 (19)
Mentions that the spleen has immune function	66 (74)	53 (85)	13 (48)
Trauma as an indication	64 (72)	47 (76)	17 (63)
Any nonmalignant heme indication	73 (82)	51 (82)	22 (81)
Any malignant indication (heme or non-heme)	56 (63)	43 (69)	13 (48)
Mentions that the surgery can be performed by laparotomy or laparoscopy	57 (64)	48 (77)	9 (33)
General anesthetic involved	45 (50)	43 (69)	2 (7)
Any perioperative complication	48 (54)	40 (65)	8 (30)
Long-term risk of infection beyond postoperative period	75 (84)	53 (85)	22 (81)
Need for vaccination at least mentioned	70 (79)	51 (82)	19 (70)
Pneumococcal vaccine mentioned	55 (62)	41 (66)	14 (52)
Hemophilias vaccine mentioned	24 (27)	13 (21)	11 (41)
Meningococcal vaccine mentioned	31 (35)	19 (31)	12 (44)
Recommends repeat pneumococcal vaccine in 5–10 years	18 (20)	14 (23)	4 (15)
Indicates that vaccines should ideally be given at least 2 weeks before surgery	31 (35)	20 (34)	10 (37)
Recommends annual influenza vaccine	12 (14)	7 (11)	5 (19)
Recommends seeking medical advice for even minor symptoms/illness	45 (51)	42 (68)	3 (11)
Recommends seeking medical advice before travel	21 (24)	18 (29)	3 (11)
Recommends wearing a medical alert bracelet or carrying a splenectomy card	15 (17)	12 (19)	3 (11)
At least mentions that antibiotic prophylaxis may be offered	60 (67)	46 (74)	14 (52)
Glossary or explanation of medical terms	30 (34)	26 (42)	4 (15)

overall quality of the information on the website. Finally, we only examined English-language websites, therefore our results are not generalizable to websites in other languages.

Conclusion

We found that websites for asplenic patients in general lacked important information about the condition; however, the websites did consistently emphasize the critical details about the long-term risk of infection and the need for vaccination. Websites were inconsistent with respect to adhering to standards recommended by quality-assessment instruments, and the text was written at a level far above what is recommended for patient literature. Physicians should keep in mind both the strengths and limitations of information on the Internet when counselling patients pre- and postsplenectomy. Physicians can use our findings to identify websites to recommend to patients or develop educational materials of their own.

Competing interests: None declared.

Contributors: Drs. Downing, Omar and McCarthy designed the study. Drs. Downing and Omar acquired the data, which Drs. Downing, Omar and Sabri analyzed. Dr. Downing wrote the article. All authors reviewed the article and approved its publication.

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